

**Special Medical Services  
INFORMATION AND REFERRAL  
SFY 2005**



New Hampshire Department of Health and Human Services  
Office of Medicaid Business and Policy  
Bureau of Medical Services  
Special Medical Services Section

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## About Information and Referral

The New Hampshire Title V Program for Children with Special Health Care Needs, Special Medical Services (SMS), provides information and referral regarding children with special health care needs as a public service. Children with special health care needs (CSHCN) are defined as those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally<sup>1</sup>.

The SMS information and referral (I&R) service is available through telephone access, the SMS website, e-mail, and paper correspondence. The service is provided directly by SMS staff and via state-funded contracts with other providers. This report does not include data from the contracted organizations (NH Family Voices, Parent-To-Parent of NH), which submit their own separate annual reports.

The Information and Referral Report has previously been prepared on a calendar-year basis. Beginning with State fiscal year (SFY) 2005, Special Medical Services converted to state fiscal year reporting. The I&R database now includes web-based inquiries reported from the State website in addition to the telephone inquiries.

The data, combined with reports from the contracted services, are being used to improve the overall public information and referral system for CSHCN in New Hampshire by providing accurate information for SMS policy discussions, program planning and budget allocations.

The Special Medical Services information and referral number is 1-800-852-3345, Ext. 4488. E-mail inquiries can be directed through the NH Department of Health and Human Services website at [www.dhhs.state.nh.us](http://www.dhhs.state.nh.us).

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<sup>1</sup> McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102:137-140.

## Information and Referral FY'05 Report

The Special Medical Services (SMS) public help-line received 210 telephone inquiries about health-related subjects and concerns from July 1, 2004 through June 30, 2005 (Chart 1). The number of direct calls to SMS for information and referral (I&R) continues a steady downward trend, from 1,069 in 1995. This is partially the result of transitioning direct care services and specialty clinics to the private sector. However, it is primarily due to contracting with community-based organizations to provide information and referral to the public via telephone and web sites.

The SMS I&R Report does not include the calls to these contracted providers, New Hampshire Family Voices and Parent-to-Parent of New Hampshire. That data is reported separately by those organizations and averages 1,200 calls yearly. Combined with the direct SMS calls, this indicates a 24% increase in volume over the past ten years. The external I&R services that SMS funds through these contracts makes a major contribution to the enhancement of public access to specialized information, referral and support for families and others concerned about children with special health care needs.

Of the 210 calls received directly by SMS, 82% were in reference to children (Chart 2) and 53% were from a parent, family member or friend (Chart 3). Hillsborough, Rockingham and Merrimack counties contributed over 65% of the calls where the county was known (Chart 4a). Belknap County, however, contributed the highest call rate based on the county population, at a rate over 30% higher than the next highest rate (Chart 4b).

The conditions that callers have commonly referenced over the past several years have been assigned to broad categories for reporting purposes. Over 200 specific medical and psychiatric diagnoses were reviewed prior to database programming by a team of pediatric physicians and the Section Administrator for Special Medical Services. Diagnoses were assigned to 19 categories or Condition Groups (Table 4). There were 172 condition-specific calls. The top five health categories referenced were:

- Nervous System/Brain (16%)
- Autism (13%)
- Developmental Issues (8%)
- Genetic/Birth Defects (8%)
- Mental Health (7%)

Chart 5 indicates the number of calls per condition for all conditions referenced. Table 1 lists the broad Condition Groups and the number of calls referencing each group.

Caller concerns are grouped into broad themes: Health, Support, School, Literature, Respite, Basic Needs and Other/Information. Approximately 30 sub-topics are included within the groups (Figure 1). Approximately 28% of the calls reference multiple concerns; therefore, the number of concerns at 100% (n=292) exceeds the number of single calls at 100% (n=210). Health issues constituted 64% of the concerns referenced (Chart 6).

Where age was referenced, less than 5% of the calls were in regard to adults over age 20. Children between the ages of birth and 4 were referenced in 27% of the calls where age was identified (Chart 7).

The services rendered by SMS staff responding to calls for information and referral are grouped into 6 broad categories: Emotional Support, Verbal Information, Parent Match, SMS Application, Written Materials Sent, Technical Assistance and Other (Figure 2). Multiple services were provided for 13% of the callers. The primary service was the provision of verbal information, followed by mailed materials (Chart 8).

Those responding to information and referral calls made 307 referrals to a wide variety of agencies, services and organizations (Chart 9). Over 30% of callers received more than one referral. Referrals to statewide and community organizations constituted 53% of referrals. These organizations are comprised of parent groups, health care providers, specialty providers, local town services, Area Agencies and other local resources. New Hampshire State agencies constituted 46% of referrals. State offices include welfare district offices, the Social Security Administration, the Department of Education, Maternal and Child Health/WIC, Medicaid/Medicare, the Division of Children, Youth and Families, Special Medical Services, and other State agencies. Special Medical Services was a referral for 22% of callers or about half of the State referrals. Table 3 provides a detailed enumeration of the referrals made.

SMS coordinators responded to 94% of the calls, with 6% of the calls being handled by other staff (Chart 10). Over half of the calls were resolved within 15 minutes, 23% involved up to a half-hour and 6% exceeded one hour in duration (Chart 11).

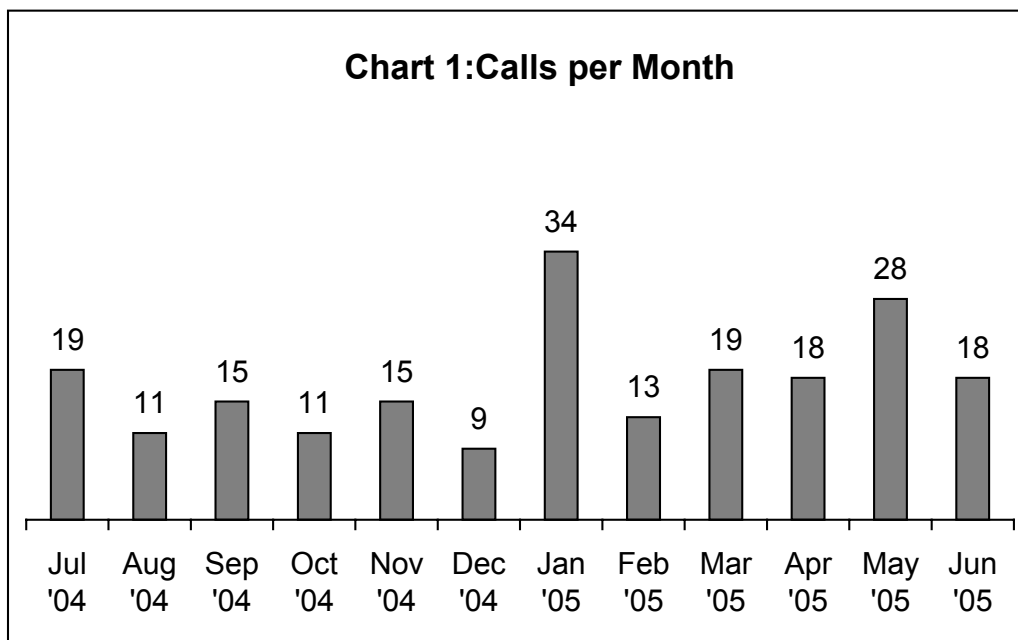
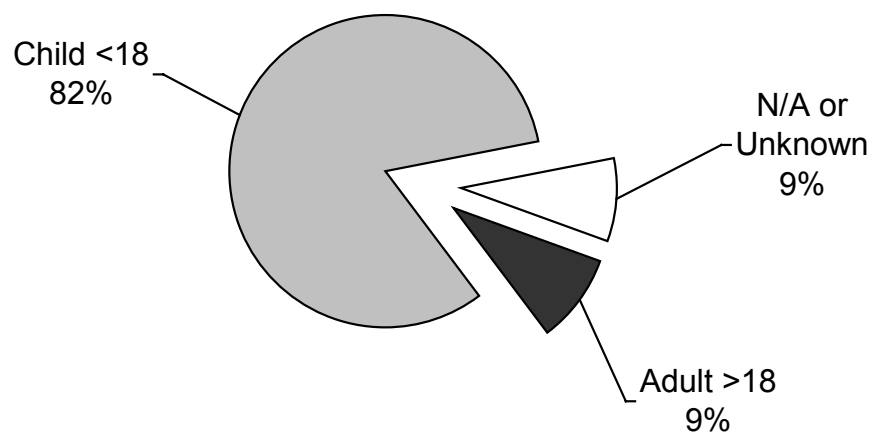
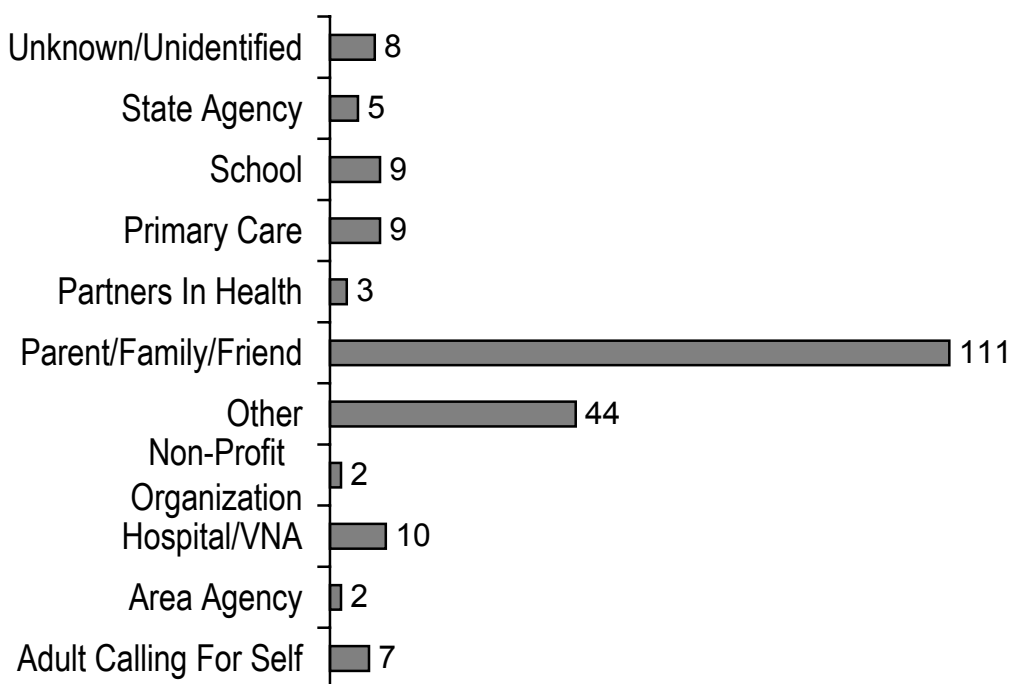


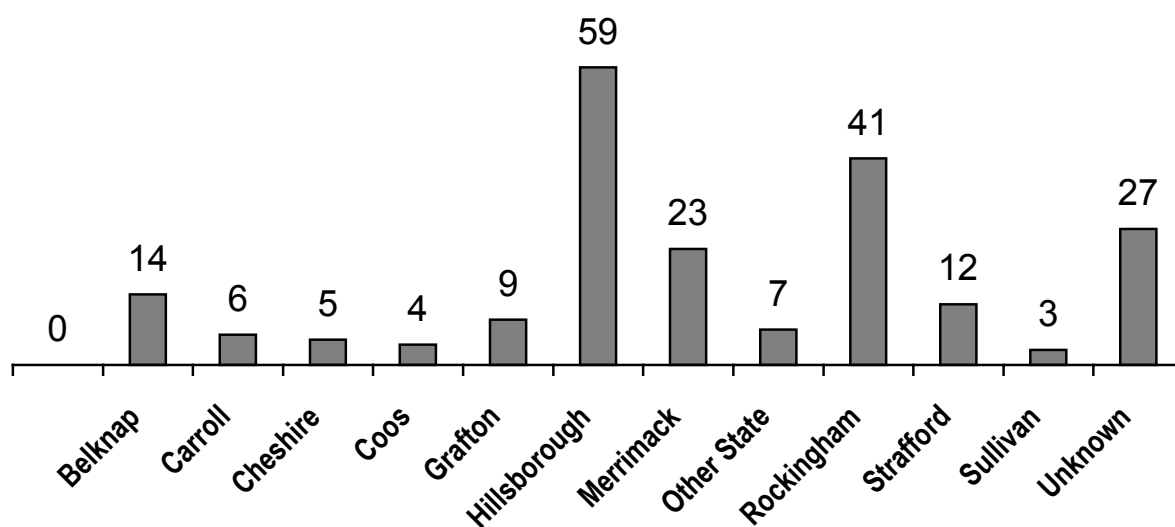
Chart 2 - Call Is About

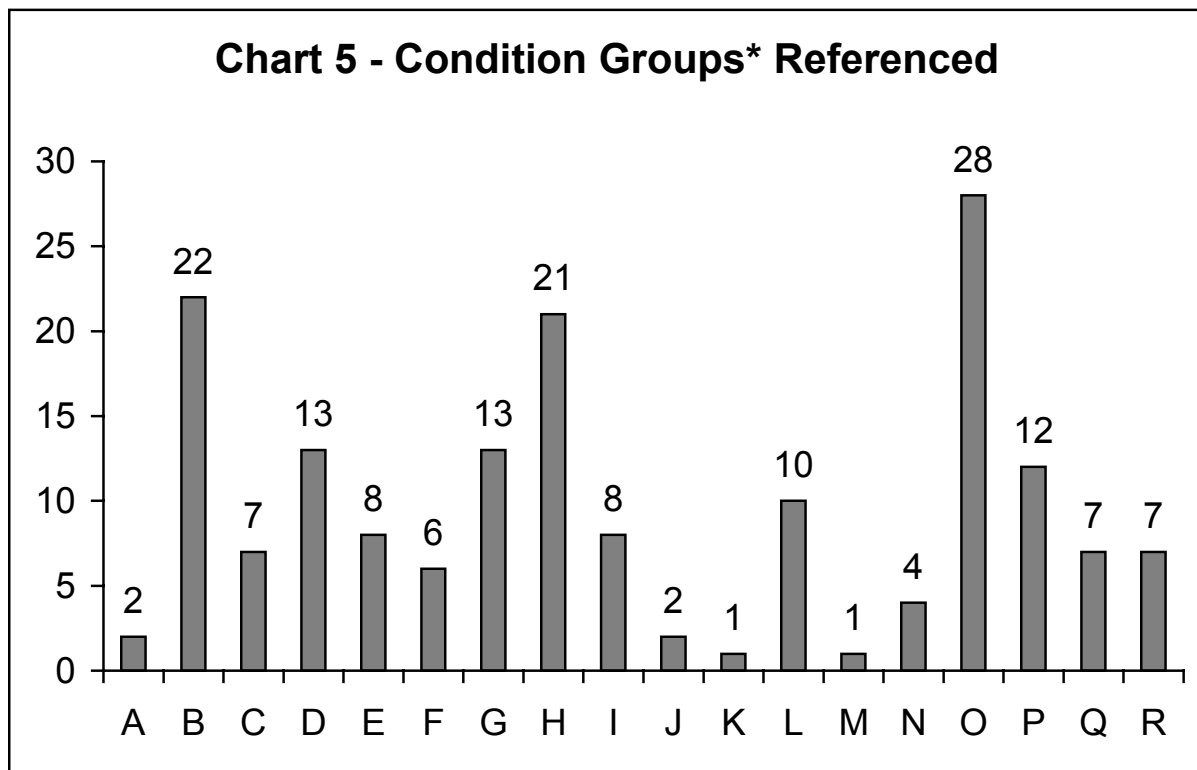
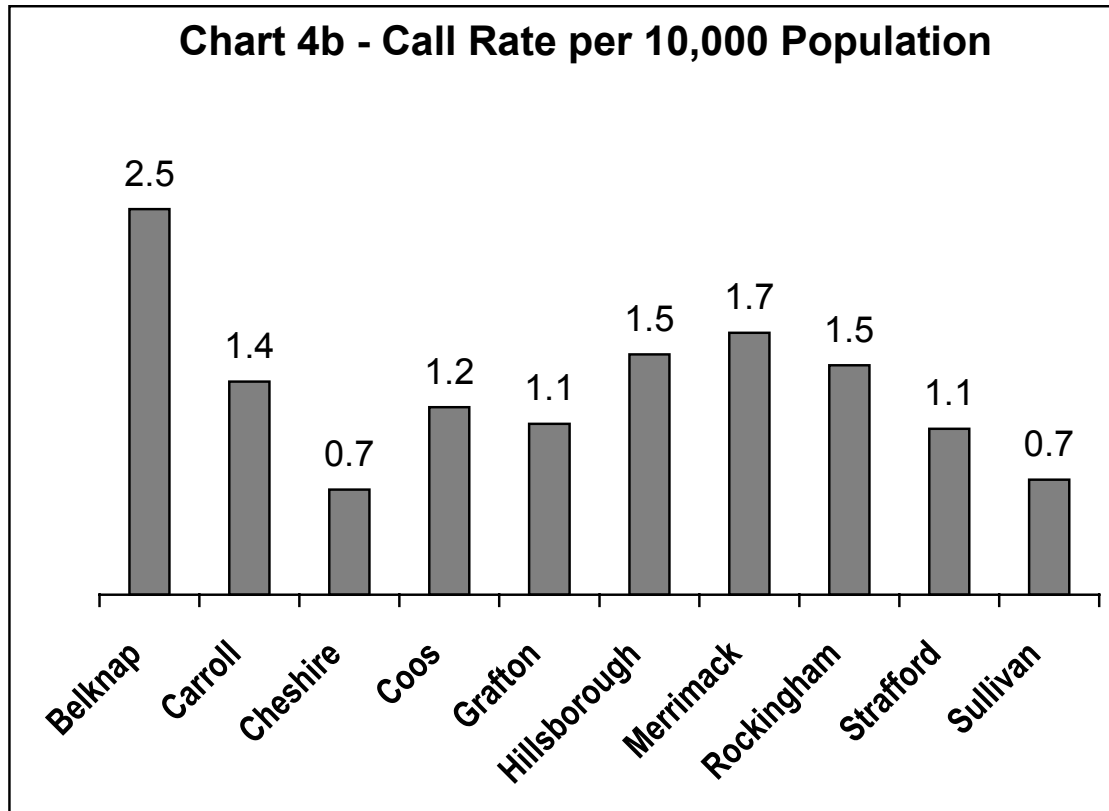


**Chart 3 - Source of Call**



**Chart 4a - Distribution of Calls by County**





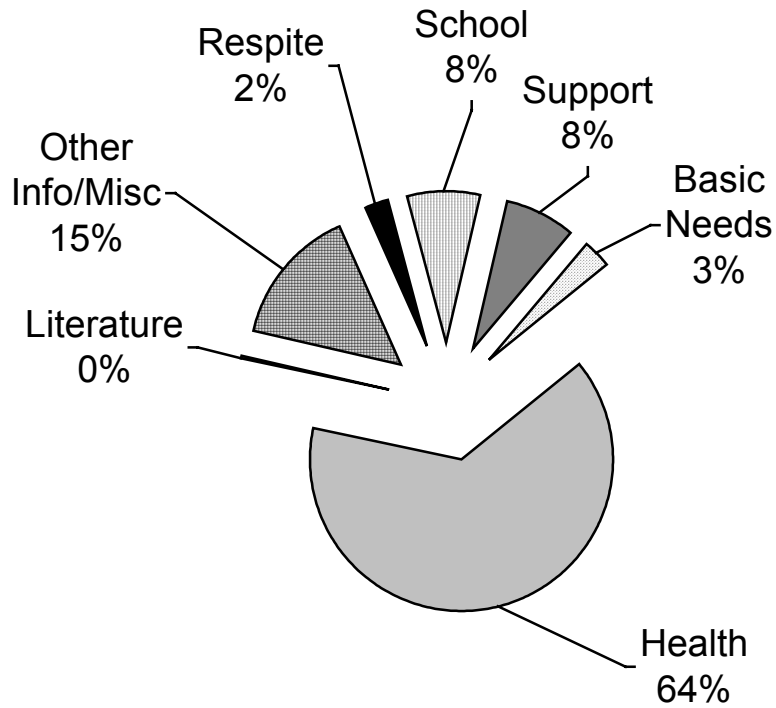


\* See Table 1 for Group Names  
Table 1

Code	Condition Group*	FY05 Calls
A	Allergies	2
B	<b>Autism</b>	<b>22</b>
C	Cardiac	7
D	<b>Development</b>	<b>13</b>
E	Endocrine/metabolic	8
F	Gastro-intestinal/genito-urinary	6
G	<b>Genetic/birth defects</b>	<b>13</b>
H	Health conditions and issues not categorized elsewhere	21
I	Hearing/vision	8
J	Hematological	2
K	Infectious disease	1
L	<b>Mental health</b>	<b>10</b>
M	Musculoskeletal system	1
N	Neoplasms	4
O	<b>Nervous system/brain</b>	<b>28</b>
P	Not a health issue	12
Q	Respiratory: Asthma	7
R	Respiratory: Cystic Fibrosis	7
S	Respiratory/circulatory: all other	0

\*See Table 4 for a detailed list of examples for each group.

**Chart 6 - Caller Concerns**



**Figure 1**

### **Information and Referral Caller Concern Groups**

**Health** generally relates to finding and accessing primary and specialty services, or technical assistance, for a wide variety of conditions, as well as health-related financial concerns such as Medicaid, insurance, SSI and help with medical bills.

**Support** generally includes listening to parents, finding self-help groups, sibling support, or supports related to parenting, child custody and so on. Parent matches are requests to link one family with another family for the purposes of support. Agency connections include linking consumers and/or professionals with local, state or national resources.

**School** requests generally relate to help with advocacy for specific school programs or services, transition to school, transition to post-school, special education issues or job training opportunities.

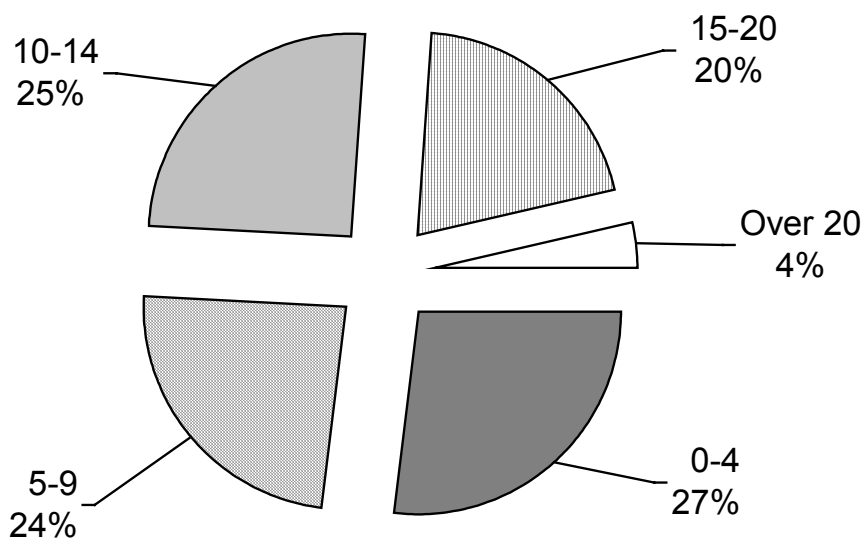
**Literature** generally includes requests for specific publications, lending library books, condition-specific information for parents, professionals or students in secondary and post-secondary schools. It also includes requests for agency informational brochures and Internet resources.

**Respite** generally relates to concerns about daycare, recreation issues or home health care to provide the primary caregivers with temporary relief from responsibilities.

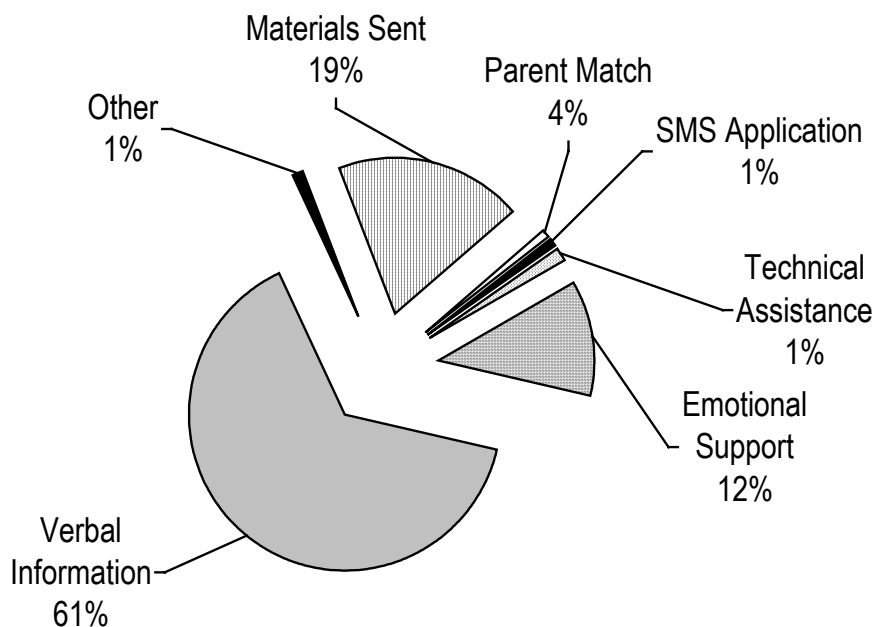
**Basic Needs** generally relates to inquiries regarding food, shelter, clothing and transportation.

**Other information** generally includes requests for information not classified elsewhere, or concerns about issues not otherwise categorized such as adoption, disability-related advocacy, training needs or legal assistance.

**Chart 7 - Age Referenced**



**Chart 8 - Services**



**Figure 2**

### Information and Referral Services Provided

**Materials Sent** generally refers to the provision of literature, written correspondence (including e-mail) and the mailing of applications.

**Verbal Information** generally refers to telephone communications about any topics, conditions or services.

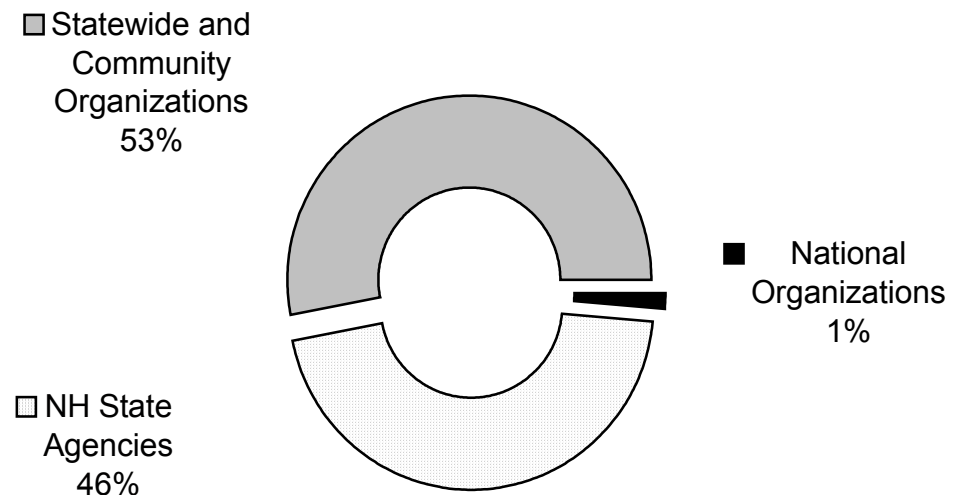
**Emotional Support** generally refers to empathic listening and problem solving.

**Parent Matching** refers to linking a parent with another parent for ongoing support and information. The Parent-to-Parent Upper Valley Support Group provides this service under contract with SMS, and reports that data in their annual report.

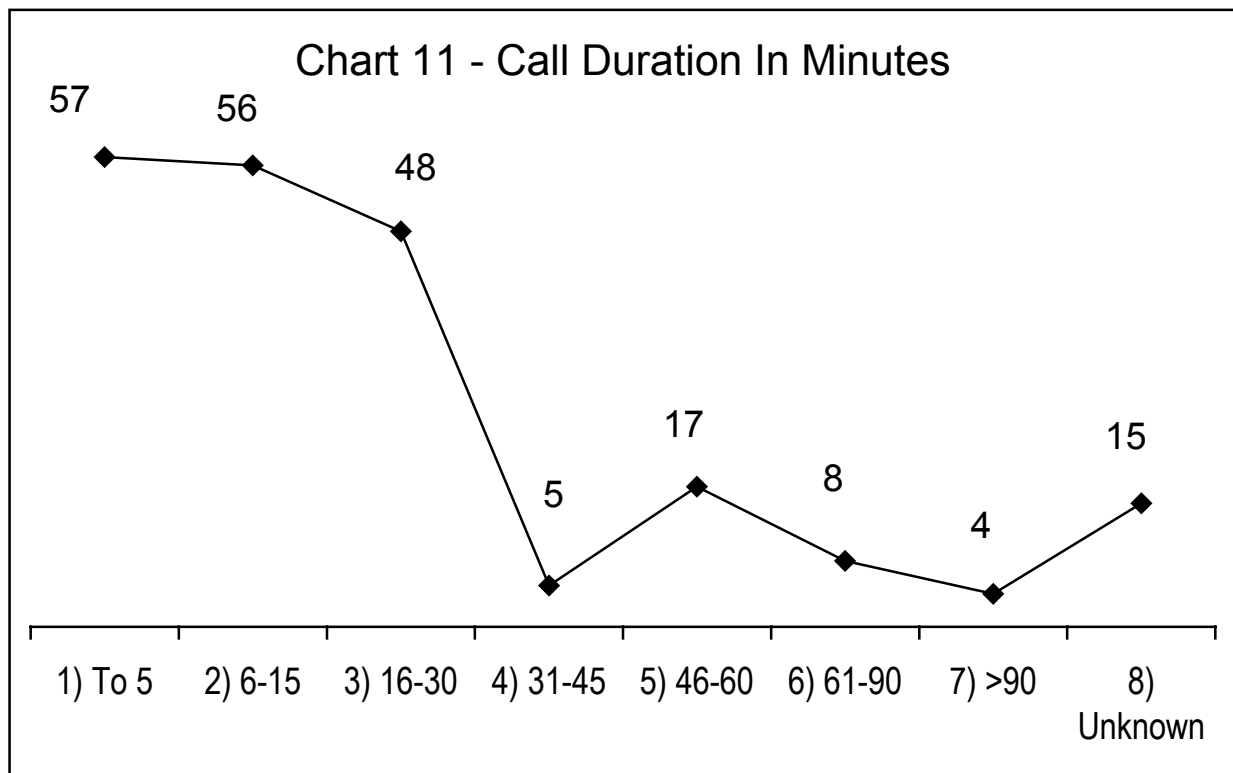
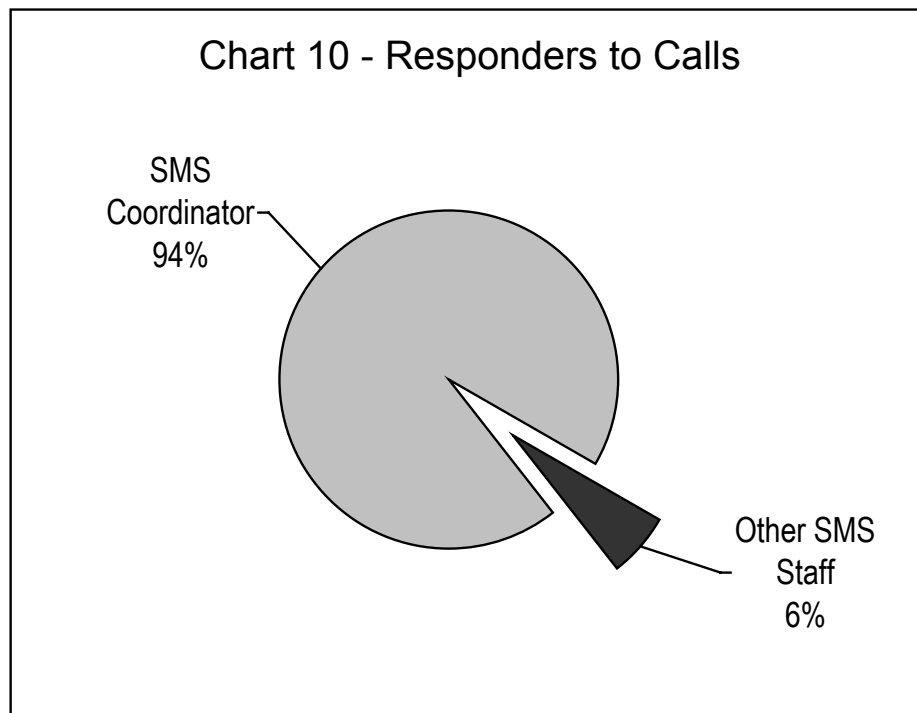
**Technical Assistance** generally refers to the provision of consultation, or assistance in the area of advocacy, or with coordinating meetings or groups.

**Other/Unknown** refers to services not captured by the other categories or not reported.

### Chart 9 - Referrals



<b>Table 4: Referrals</b>	<b>Agency</b>	<b>Count</b>	<b>Percent</b>
National/Regional Organizations	Nation/Region/Listserve	4	1.3%
NH State Agency	BH/DDS	2	0.7%
NH State Agency	District Offices	14	4.6%
NH State Agency	DOE/Voc Rehab	1	0.3%
NH State Agency	Other State Agency	55	17.9%
NH State Agency	SMS	68	22.1%
Statewide and Community Organizations	Condition Specific Org	7	2.3%
Statewide and Community Organizations	Early Intervention	4	1.3%
Statewide and Community Organizations	Food/Shelter/Clothing	2	0.7%
Statewide and Community Organizations	Local Health Care	11	3.6%
Statewide and Community Organizations	Mental Health Ag/Provider	37	12.1%
Statewide and Community Organizations	NH Family Voices	1	0.3%
Statewide and Community Organizations	Other	19	6.2%
Statewide and Community Organizations	Other Disability Orgs	10	3.3%
Statewide and Community Organizations	Other Parent/Advocacy Groups	1	0.3%
Statewide and Community Organizations	Parent to Parent	11	3.6%
Statewide and Community Organizations	Partners in Health	29	9.4%
Statewide and Community Organizations	Spec Ed/School	9	2.9%
Statewide and Community Organizations	Specialty provider	16	5.2%
Statewide and Community Organizations	Town Services	6	2.0%



**Table 4: Master List for I&R Calls: Health Conditions Commonly Referenced**

<b>Reporting Groups</b>	<b>Examples</b>
<b>Allergies</b>	Adverse drug reaction, environmental, food allergies
<b>Autism</b>	Asperger's Syndrome, autism, autism spectrum disorders (ASD), pervasive developmental delay (PDD)
<b>Cardiac</b>	Cardiac anomalies, cardiac transplant, congenital heart, heart problems, heart surgery, hypoplastic left heart Syndrome (HLHS), patent ductus arteriosus (PDA), tetralogy of fallot, ventricular septal defect (VSD)
<b>Development</b>	Delayed speech, developmental delay (DD), failure to thrive, mental retardation (MR), prematurity,
<b>Endocrine/Metabolic</b>	Diabetes, hyperglycemia, phenylketonuria (PKU)
<b>Gastro-intestinal/Genito-urinary</b>	Bed wetting, Chron's Disease, chronic constipation, colitis, digestive disorders, dysphagia, G-tube, gastric bleed, gastroenteritis, Hirschprung's Disease, hypospadias, illiostomy, J-tube, open bladder, Prune Belly Syndrome (PBS), reflux disease (GERD), renal disease, ulcerative colitis, ulcers, vomiting, weight gain
<b>Genetic/Birth defects</b>	Adrenal leukodystrophy (ALD), chromosomal abnormalities, chromosomal deletion, cleft lip, cleft palate, congenital diaphragmatic hernia, Down Syndrome, Dubowitz Syndrome, femoral hyperplasia facies syndrome, fetal alcohol or drug syndrome or effects (FAS/FDS, FDS/FDE), Fragile X Syndrome, Marfans Syndrome, Martin-Bell Syndrome, multiple congenital anomalies (ECC Syndrome), neurofibromatosis, Noonan Syndrome, osteogenesis imperfecta, Pffeiffer Syndrome, Prader-Willi Syndrome (PWS), Proteus Syndrome, Rubenstein-Taybi, soft palate insufficiency, trisomy 9, trisomy 21, tuberous sclerosis
<b>Other health condition</b>	Abuse, assault, burns, chronic health conditions/unspecified, complicated pregnancy, dental, lead poisoning, medication issues, orthodontia concerns, sudden infant death syndrome (SIDS), unnamed health condition, unable to categorize within available selections
<b>Hearing/Vision</b>	Blind, deaf, glaucoma, hearing impaired, Moebius Syndrome, Stargardt's Disease, vision impaired
<b>Hematological</b>	Hemophilia, leukemia, sickle cell disease, X-linked hypogammaglobulin anemia
<b>Infectious disease</b>	Cytomegalovirus, hepatitis, HIV/AIDS, meningitis, tuberculosis (TB)
<b>Mental health</b>	Anxiety disorder, attachment disorder, attention deficit disorder (ADD), attention deficit hyperactivity disorder (ADHD), bi-polar disorder, depression, oppositional defiant disorder (ODD), reactive attachment disorder, schizophrenia, serious emotional disturbance (SED), substance abuse
<b>Musculoskeletal system</b>	Amputation prothesis, arthrogryposis (no biceps), chronic fatigue, fibromyalgia, juvenile rheumatoid arthritis (JRA), low tone, Lupus, muscular dystrophy, orthopedic, torticollis
<b>Neoplasms</b>	Cancer, Hodgkins Disease, leukemia, myosarcoma, osteosarcoma, retinoblastoma



## I&R Health Conditions Referenced by Callers (cont'd)

Reporting Groups	Examples
<b>Nervous system/brain</b>	Agensis of the corpus callosum, anacephaly, apraxia, ataxia, Canavan's Disease, cerebral palsy (CP), cerebrovascular accident (CVA), dyslexia, dyspraxia, dystonia, encephalitis, epilepsy, familial spastic diplegia, Huntington's Chorea, Hurler Syndrome, hydrocephalus, hypotonia, Landau Kleffner Syndrome (LDS), learning disorders (LD), Lennox Gastaut Syndrome, medium chain acylCoAdehydrogenase (MCAD), microcephalus, mitochondria disorder, mitochondria myopathy, neurodevelopmental delay (NDD), neuromotor issue, non-verbal learning disability (NLD), Opsoc/Onus-myoclonus Syndrome, paraplegia, quadriplegia, Rett Syndrome, schizencephaly, seizure disorder, septo optic pituitary dysplasia (SOPD), spina bifida, spinocerebellar, stroke, Sydenham's Chorea, Tourett's Syndrome, traumatic brain injury (TBI)
<b>Not a health issue</b>	Issues such as insurance questions, needing help with social or community services, seeking help with medical bills
<b>Respiratory: Asthma</b>	Asthma
<b>Respiratory: Cystic Fibrosis</b>	Cystic Fibrosis (CF)
<b>Respiratory/Circulatory: all other</b>	Churg Strauss Syndrome, intubated, pneumonia, pulmonary condition, pulmonic valvular stenosis, reactive airway disease, subglottal stenosis, trach dependent
<b>Dental</b>	Orthodontia, oral health
<b>Not listed</b>	Not listed